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Section: LIFE

WOMEN, DES AND DECADES OF DESOLATION

Kim Painter

Susan Simpson was just 19 when she went for her first pelvic exam, learned she had cancer - and was told the cure would mean removal of her ovaries, uterus and vagina.

Today, at 35, she's a successful accountant who sings at church services and weddings in Macon, Ga. She is cancer-free.

But she's not over her illness. Every time Simpson urinates she must insert a catheter in her urethra. When she starts a serious relationship with a man, she must explain that she cannot have children and that her reconstructed vagina is not quite the same as other women's. And, every day, she must deal with her anger. That anger is shared by countless U.S. women who've suffered genital cancer, miscarriages and other reproductive difficulties because, scientists say, their pregnant mothers took diethylstilbestrol - DES - a synthetic hormone meant, ironically, to prevent miscarriages.

"I've come to terms with it now and I have people in my life who are supportive and really good friends," says Simpson, who is divorced. "But, damn it, I shouldn't have to deal with it."

The Food and Drug Administration banned DES use by pregnant women 20 years ago this month, soon after researchers linked the drug to a rare cervical and vaginal cancer in daughters of women who took it. But the ban came 30 years after well-meaning doctors began prescribing DES to an estimated 3 million pregnant U.S. women.

About 300 companies sold DES for miscarriage prevention. Those companies - still fighting lawsuits - insist the statistical link between DES and the rare cancer doesn't prove it caused the cancer.

That link first came to light in early 1971, when doctors at Massachusetts General Hospital in Boston reported the rare vaginal and cervical cancer, called clear cell adenocarcinoma, in eight girls and women ages 14 to 22. They had one thing in common: Their mothers took DES during pregnancy.

Since then, scientists have discovered structural abnormalities in the reproductive organs of women - and some men - whose mothers took DES. DES daughters also have high rates of menstrual problems, tubal pregnancy, miscarriage and premature delivery. As many as half have some reproductive problem, research

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suggests.

The vaginal and cervical cancer is, by comparison, rare, affecting 1 in 1,000 DES-exposed daughters. Since 1971, Dr. Arthur Herbst of the University of Chicago, one of the doctors who found the original eight cases, has counted 580 clear cell cancer cases and documented DES exposure in 62%. The remaining cases likely include some that are DES-related and some that are not, Herbst says.

About 80% of DES-exposed cancer victims survive. But because the cancer strikes such young women - the risk peaks at age 19 - and because it is so devastating, it is perhaps the most disturbing legacy of DES.

Margaret Lee Braun, diagnosed at 19 and now 39, has lived with that legacy for $20\ \mathrm{years}$.

"Just as you are discovering a sense of your own sexuality, you receive a kind of physical and psychological blow that few people have ever tried to cope with," says the co-founder of The DES Cancer Network. "In a sense, you're a reluctant survivor. You're harmed by medical technology and then saved through medical technology, through this very radical treatment in which your insides are either fried out, so nothing functions properly again, or your insides are cut out."

Braun, who lives in Rochester, N.Y., with her husband of eight years, had surgery - removal of her vagina, uterus, ovaries and bladder, followed by vaginal reconstruction. For a long time afterward, she couldn't talk about what had happened.

"It is so hard to say the word vagina," Braun says. "Women don't even want to say where it happened."

Then, several years after her surgery, Braun began to meet other survivors who, like her, were suing DES makers. The women shared medical and legal horror stories and talked about how they got on with their lives.

Those discussions led to the formation of the network, which publishes newsletters, lobbies health officials and holds annual meetings for the far-flung survivors.

The most recent meeting, held in Los Angeles in October, attracted 25 women - all with painful stories to tell.

One was Georgiann Kensinger, a 32-year-old Los Angeles divorcee who was diagnosed at 15.

"I remember wishing at the time that I had brain cancer," she says. "There were 10 doctors at a time coming in and oohing and ahhing over your cervix. It was not only terribly frightening, it was humiliating."

Network co-founder Susan Helmrich, now 36 and living in Berkeley, Calif., with her husband and adopted son, was 21, just out of college and planning medical school when it happened to her.

"My first question was, 'Was it serious?' My second question was 'Would I be able to have children?' The doctor said 'no' and I cried. It seemed so unreal to me," says Helmrich. She became a health researcher instead of a physician.-

Marsha Mainzer, 38, a divorced real estate appraiser from Virginia Beach, Va.,

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was 17. Her parents refused to let doctors remove her reproductive system.

So she got radiation treatment. "I was literally fried inside. My ovaries died. My fallopian tubes shriveled up. I found out I was born without a vaginal canal up high, as a result of the DES. My uterus is still there."

The treatment blackened the skin on the lower part of her body and damaged her colon. Eventually, Mainzer had to have a colostomy, an operation that allows discharge of feces into a disposable bag worn outside the body.

Difficulties with bladders, colons and reconstructed vaginas are common among survivors, says Dr. Leo Lagasse, a gynecological cancer specialist who spoke at the meeting and practices at Cedars-Sinai Medical Center in Los Angeles. However, he says, surgery and radiation techniques have improved considerably in the past 20 years.

Like all cancer survivors, survivors of this cancer live with the fear of recurrences. New cases have been reported up to 20 years after the initial cancer. Network members want to know how common such cases are.

They also want to know how many of their DES-exposed sisters are still at risk. Initial cases, still occurring, have been reported in exposed women as old as 41.

Other important questions - such as whether mothers who took DES have an increased breast cancer risk - have not been answered, Braun says.

The "myth is that the DES story is over," Braun told officials at the National Institutes of Health last spring. She hopes the government's new emphasis on women's health research will bring the spotlight back to DES, which has attracted little research money in recent years.

In any case, she and her fellow survivors, long silent, will keep talking.

"This kind of thing should never have happened to us," says Simpson, the Macon church singer. "It should never have happened to women."

Where to get information

For information on DES-related cancer, write the DES Cancer Network at P.O. Box 10185, Rochester, N.Y. 14610. For other information on DES, write DES Action USA at 1615 Broadway, Oakland, Calif. 94612.

EAR CUTLINE: BRAUN: Survivors help each other

CUTLINE: LINGERING ANGER: Cancer survivor Susan Simpson, 35, had her reproductive organs removed after her diagnosis at age 19.

EAR PHOTO color, Jim Ruymen PHOTO color, Jim Ruymen

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